



CONSUMER ENGAGEMENT FRAMEWORK

When and how to engage with consumers

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This is a living document. It will be routinely reviewed and updated in accordance with emerging evidence, organisational priorities and perspectives

Independent, not-for-profit and evidence based, NPS MedicineWise enables better decisions about medicines and medical tests.



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Contents

BACKGROUND	2
About this document.....	2
Links with organisational strategy	2
Consultation process	3
Who are consumers?	4
NPS MEDICINEWISE CONSUMER ENGAGEMENT MODEL	5
BUILDING MEDICINES LITERACY	6
PRINCIPLES AND STRATEGIES FOR CONSUMER ENGAGEMENT....	7
OUR APPROACH TO CONSUMER ENGAGEMENT	9
Systematically engage with consumers	9
Embed consumers in organisational governance	9
Collaborate with Consumers Health Forum of Australia	10
Focus on long term implementation	10
Monitor engagement and evaluate impact.....	10

BACKGROUND

About this document

NPS MedicineWise is committed to involving consumers, so that they can influence the work that we do and participate in the development of our programs, products and services. This document outlines why, when and how NPS MedicineWise will involve consumers.

Importantly, it will support NPS MedicineWise to honour the primacy of consumers in our execution of our role as stewards of Quality Use of Medicines in Australia

Links with organisational strategy

The [NPS MedicineWise strategy](#) has emphasised the organisation's focus and commitment to keep consumers at the heart of all that we do – to ultimately achieve better health outcomes for all Australians.

Central to this commitment is our pledge to genuinely engage with consumers, communities and organisations at all levels of the organisation and throughout the process of developing all our programs, products and services.

Consumer engagement is a requirement of the ISO Quality Standards and supports *Standard 2: Partnering with Consumers* developed by the Australian Commission on Safety and Quality in Health Care (ACSQHC).

NPS MedicineWise will seek to gain the insights of consumer knowledge and experiences, from a diverse range of people, with particular attention to the following priority people/ groups:

- ▷ Taking multiple medicines
- ▷ Those with chronic conditions
- ▷ Older people
- ▷ Carers
- ▷ Aboriginal and Torres Strait Islanders
- ▷ Those starting new medicines.

Consultation process

This Consumer Engagement Plan has been developed in two main stages.

Stage 1

A consumer workshop was conducted in September 2019, which helped to set the broad direction for this paper. Participants of the workshop included representatives from:

- ▷ Jo Root, Jan Donovan and Mark Diamond from Consumers Health Forum of Australia (CHF)
- ▷ Naomi Poole from Australian Commission on Safety and Quality of Health Care (ACSQHC)
- ▷ Consumer representatives from NPS MedicineWise advisory groups:
 - Anne McKenzie (Data Governance Advisory Group)
 - Diane Walsh (Prescribing Competencies Framework Expert Reference Group)
 - Debra Kay (Clinical Intervention Advisory Group)
- ▷ Anthony Carr, Sarah Spagnardi and Teresa Vaccaro from NPS MedicineWise

Stage 2

Feedback on this Consumer Engagement Plan has also been provided by:

- ▷ Condition Specific Organisations
 - Janelle Woods from Beyond Blue
 - Carolyn Jones from Diabetes Victoria
 - Anthony Flynn from Asthma Australia
 - Carol Bennett and Priyanka Rai from Painaustralia
 - Natalie Raffoul from National Heart Foundation
 - Andrew Mills and Franca Marine from Arthritis Australia
- ▷ Consumer Organisations
 - Leanne Wells and Jo Root from Consumers Health Forum of Australia (CHF)
 - Daniel Coase from Federation of Ethnic Communities' Councils of Australia (FECCA)
 - Kate Gorman from Health Consumers Association of ACT
 - Melissa Fox and Jo Smethurst from Health Consumers Queensland
 - Ara Creswell and Samara McCann from Carers Australia
 - Corey Irlam and Jill Moran from Care of the Ageing (COTA)
 - Clare Mullen from Health Consumers' Council WA
- ▷ Aboriginal and Torres Strait Islander Organisations and communities
 - Mike Stephens from National Aboriginal Community Controlled Health Organisations (NACCHO)
 - Kelly Dingli from Queensland Aboriginal and Islander Health Council (QAIHC)
 - Steve Renouf, Aboriginal and Torres Strait Islander representative
- ▷ Primary Health Networks
 - Brodie Preston from North Western Melbourne PHN
 - Stacey Leavens and Yolanda McKean from Capital Canberra PHN
 - Jane Harwood, Debra Royale, Lucy Patel, Nicola Blacker and Tim Benson from WA Primary Health Alliance (WAPHA)

This plan (either partially or in full) has also been presented to the Clinical Intervention Advisory Group (CIAG), Executive Team and the NPS MedicineWise Board for feedback.

Who are consumers?

- ▷ **Consumers** are people who are users, or potential users of healthcare services (including their families and carers). In this context they are being engaged in partnership with NPS MedicineWise to improve the quality and useability of programs products and services that we develop. Consumers are not healthcare professionals, service providers or employees of NPS MedicineWise.
- ▷ **Consumer representatives** are a consumer, carer or community members who are capable of reflecting a broad consumer view, not just their own (although they don't represent all consumers). They are usually nominated by, an organisation of consumers, carers or community members. They may or may not represent the formal views of, and report back to, a particular group.
- ▷ **Communities** are a group of consumers, who have been brought together by a common purpose, interest or experience, such as a condition, geographical location, health service use, shared experience or interest, culture or life circumstance, population or their role in the healthcare environment.
- ▷ **Consumer organisations**, in this context, refers to all organisations who provide NPS MedicineWise with consumer insights. They may be:
 - peak consumer organisations, such as CHF and its state affiliates
 - community specific groups, such as FECCA, NACCHO or Carers Australia
 - disease organisations, such as Arthritis Australia, Painaustralia, Diabetes Australia or any of their state affiliates; and
 - Primary Health Networks.

Other definitions:

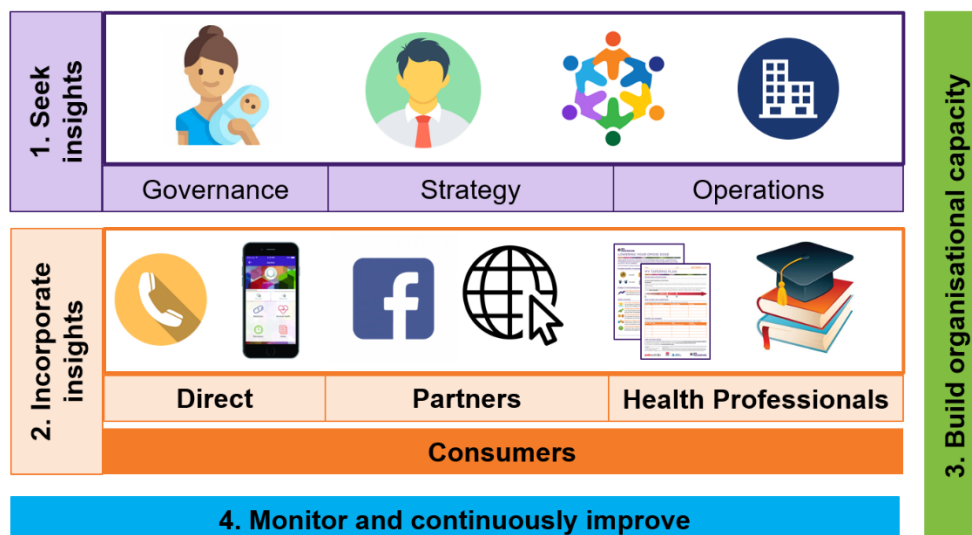
- ▷ **Engagement** refers to any activity that incorporates consumer insights, experience and needs into decision making. This is sometimes also referred to as consumer involvement or participation.
- ▷ **Patients** are people who are receiving medical services because of a problem or check-up.

NPS MEDICINEWISE CONSUMER ENGAGEMENT MODEL

The Consumer Engagement Model below has four key aspects:

1. **Seek consumer evidence and insights** from consumers, consumer representatives, communities and consumer organisations. These will be embedded across all levels of the organisation (through the Board, Advisory Groups and Project teams) and throughout projects (from setting priorities, design, development, implementation and evaluation).
2. **Incorporate insights** to inform all programs, products and services. Products and services reach consumers in three key ways
 - a. direct to consumers (such as via Medicines Line or MedicineWise app)
 - b. through partners (such as disease organisations, PHNs or researchers)
 - c. via health professionals. NPS MedicineWise develops health professional mediated resources (Patient Action Plans, Patient Decision Aids and Factsheets), however greater focus will be placed on supporting health professionals to communicate with patient and carers as well as helping build medicines literacy (see *Building Medicines Literacy*)
3. **Build organisational capacity** through training and support. Focus on supporting the consumers we work with, NPS MedicineWise staff broadly, project teams, partners and the environment.
4. **Monitor and continuously improve** by actively seeking feedback from consumers, partners and health professionals and incorporating feedback. Evaluation goes beyond qualitative data e.g. website hits, number of downloads etc, but aims to measure the impact of our work on consumer behaviour and experience. We will also evaluate the effectiveness of our engagement strategies to inform areas for improvement.

FIGURE 1: CONSUMER ENGAGEMENT MODEL



BUILDING MEDICINES LITERACY

The Australian Commission on Safety and Quality in Health Care defines individual health literacy as the skills, knowledge, motivation and capacity of a person to access, understand, appraise and apply information to make effective decisions about health and health care and take appropriate action. This definition can also be applied to context of medicines and medical tests.

There are many factors that contribute to individual and environmental literacy, and therefore many different strategies and approaches that can be used to bring about improvements. Strategies are needed both to build the capacity of people to understand the choices they have, and to build the capacity of the health system to support, encourage and allow this to occur.

TABLE 1: ACTIONS THAT CAN BE TAKEN TO ADDRESS MEDICINES LITERACY

Role	Possible actions
Consumers	<ul style="list-style-type: none"> ▷ Discuss with healthcare providers any difficulties in understanding information and services ▷ Ask family, friends and support services (such as translating services) for help with communication difficulties ▷ Ask for more information about any part of care that is unclear ▷ Be open and honest with healthcare providers about medical history and medications ▷ Improve knowledge and skills by participating in education ▷ Raise awareness among family, friends and the community about the importance of medicines literacy ▷ Become involved in the planning, design and delivery of information and services for consumers
Healthcare providers	<ul style="list-style-type: none"> ▷ Recognise the needs and preferences of individual patients and consumers and tailor their communication style to the person's situation ▷ Assume that most people will have difficulty understanding and applying complex health information and concepts ▷ Use a range of interpersonal communication strategies to confirm information has been delivered and received effectively ▷ Encourage people to speak up if they have difficulty understanding information provided ▷ Use ways of communicating risk information about treatment options to people that are known to be effective ▷ Participate in improvement projects aimed at reducing barriers to literacy within the healthcare organisation's physical environment ▷ Participate in medicines literacy education and training

PRINCIPLES AND STRATEGIES FOR CONSUMER ENGAGEMENT

NPS MedicineWise is committed to the following principles which guide our approach to all consumer engagement activities.

TABLE 2: PRINCIPLES AND STRATEGIES FOR CONSUMER ENGAGEMENT

Principle	Principle Description	Strategies
Participation	<p>Consumers have the right to participate in decisions about their own health, well-being and welfare, as well as shape the provision of services.</p> <p>A broad range of consumer engagement strategies should be incorporated to ensure accessibility for all, particularly those experiencing the greatest need and with the least opportunity to influence. The value of consumer engagement should be recognised and respected.</p>	<p>Develop a Consumer Engagement Framework (this document)</p> <p>Provide a range of engagement options for consumers, recognising that consumers may want to participate at varying levels/degrees</p> <p>Promote consumer engagement opportunities widely and broadly</p> <p>Provide staff with learning opportunities which demonstrate the value of consumer engagement brings to service provision</p>
Diversity and inclusion	<p>Consumers and their families/significant others are a diverse group. This diversity includes but is not limited to their health, the medicines they take, or medical tests they have performed, as well as cultural, age, gender, ability socio-cultural, economic and geographic circumstance.</p> <p>Given this diversity, consumer engagement opportunities need to be accessible and inclusive, with flexibility and a range of options.</p>	<p>Recognise that consumers and family/significant others are unique groups with unique issues and require specific representatives</p> <p>Engage broadly using a range of strategies to increase access and inclusion from potentially marginalised consumers by addressing known barriers to engagement.</p> <p>Consider health literacy principles in engaging with consumers</p>
Leadership and support	<p>Organisational culture must support and value consumer engagement, through leadership, knowledge, skills and processes.</p> <p>Opportunities are provided for the ongoing support, training and education of consumers to support their roles.</p> <p>Consumer engagement is resourced at an appropriate level within NPS MedicineWise and the value of their work, time and cost to consumers is recognised.</p>	<p>Articulate the organisation's commitment to consumer engagement in strategic documents</p> <p>Build organisational capacity for consumer engagement activities through policies and procedures, staff training (see <i>Long Term Implementation</i>), support and leadership</p> <p>Build consumer capacity through ensuring they have access to appropriate training and support</p> <p>Support consumer engagement from the top and resource adequately to ensure participation is meaningful</p> <p>Recognise, remunerate consumer time and input accordingly and reimburse costs including transport, childcare, carers support and internet access (in accordance with grant guidelines and obligations)</p>

<p>Meaningful and mutual benefit</p>	<p>All consumer engagement opportunities are meaningful with regard to involving consumers at the earliest opportunity, clearly identifying and explaining the role of consumers, informing consumers of the purpose of their participation, including the decision-making processes, the ability to influence outcomes and ensuring access to information and means to participate.</p>	<p>Initiate consumer engagement processes and ensure they are open, honest, inclusive, appropriate and measurable</p> <p>Allow sufficient time for meaningful engagement</p> <p>Provide information for consumers outlining their role and responsibilities, as well as the purpose of the engagement/participation activities</p> <p>Provide consumers with information that is clear, accurate, relevant and timely, recognising the different communication needs and preferences of consumers</p> <p>Build transparent processes to ensure engagement is not tokenistic and/or rubber stamping already made decisions or outcomes</p>
<p>Accountability</p>	<p>Consumer engagement activities are transparent and accountable and establish clear and measurable criteria against which the influence and success of consumer engagement can be measured. The outcomes of consumer engagement processes are provided to consumers as well as how consumer engagement is measured. Continuous improvement processes are incorporated including ongoing and regular review and evaluation.</p>	<p>Develop Consumer Engagement policies, procedures and/or protocols</p> <p>Establish clear and measurable criteria against which the success of the engagement can be measured for all consumer engagement activities.</p> <p>Provide feedback to consumers about how their contribution has influenced outcomes (or not, and why)</p> <p>Incorporate continuous improvement processes within consumer consultation, including evaluation and review of consumer engagement processes</p> <p>Ensure consumer engagement strategies are guided by current evidence and practice</p>
<p>Ethical, respectful and valued</p>	<p>The needs of consumers and their families/significant others, benefits of consumer engagement and processes are respected and valued.</p> <p>There is recognition of the impact of stigma and discrimination and the need for confidentiality, privacy and a safe environment for all consumer engagement processes.</p>	<p>Engage with consumers in a respectful way that values the contribution consumers bring to improving programs, products and services, monitoring and review, as well as overall system outcomes</p> <p>Build partnerships with consumers, through relationships, trust, openness and consistency</p> <p>Recognise the impact of stigma and discrimination</p> <p>Explain how personal information will be managed to ensure confidentiality, including the opportunity to remain anonymous</p> <p>Provide a safe, secure and welcoming environment for consumer engagement activities</p> <p>Publicly acknowledge consumer contribution to work and provide opportunities for consumers to share in success e.g. invitations to recognition events or media</p> <p>Adapt methodologies to be able to meet individual needs of participating consumers, in practical ways</p>

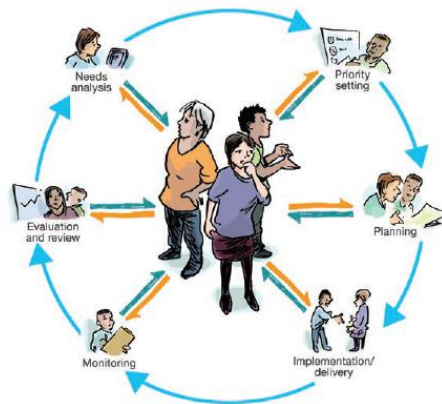
OUR APPROACH TO CONSUMER ENGAGEMENT

During the process of developing this plan, the current level of consumer engagement within key NPS MedicineWise programs, products and services was assessed. Based on this assessment the following key recommendations are proposed.

Systematically engage with consumers

To realise the benefits of consumer engagement, it is imperative that consumers are involved in all the work that NPS MedicineWise does, at all stages from setting organisational priorities, needs analysis, through design, development, implementation and evaluation.

FIGURE 2: MODEL FOR INVOLVING CONSUMERS



TAKEN FROM A GUIDE FOR HEALTH STAFF – PARTNERING WITH CONSUMERS, HEALTH CONSUMERS QUEENSLAND

Embed consumers in organisational governance

Consumers will have input into setting organisational priorities through a skills-based Board matrix, and membership on all NPS MedicineWise Advisory Groups and Expert Working Groups.

In addition, a dedicated Advisory Group will be established to advise on best practice for consumer and community engagement and hold NPS MedicineWise accountable to our obligation, commitment to follow through on the consumer engagement principles (see *Principles and strategies for consumer engagement*). Further information about the role, reporting structure and membership will be outlined in the Terms of Reference (to be developed).

Regular meetings with key external stakeholder organisations are an important mechanism for gathering consumer insights and informing the work that we do. Examples of key stakeholders include: CHF and other consumer organisations (e.g. FECCA, NACCHO and Carers Australia), condition specific organisations and Primary Health Networks (PHNs). Dissemination of consumer insights throughout the organisation will be done through a variety of channels (such as through CRM (corporate reporting system), internal communication mechanisms and attending team / project meetings).

Collaborate with Consumers Health Forum of Australia

As Australia's leading advocate on consumer health care issues and the organisation funded by the Australian Government as the national peak body for healthcare consumers, Consumers Health Forum of Australia (CHF) is a key partner for NPS MedicineWise to realise its mission of better health outcomes for all Australians. CHF brings over 250 members and other channels through which NPS can seek to engage consumers including Special Interest Groups, the Youth Health Forum and Australia's Health Panel.

Continued collaboration efforts between NPS MedicineWise and CHF will be detailed in a Working Together document. Examples of key collaboration activities include: piloting a new consumer engagement support and mentoring program which aims to build the capacity and capability of consumer representatives, particularly of those with less experience and/or from diverse backgrounds.

Focus on long term implementation

Implementing best practice consumer engagement is an ongoing process, it doesn't happen overnight. An implementation plan is currently being developed, however it is anticipated that the following components will be required:

1. Internal staff training
 - a. A small group of internal consumer engagement champions (10) who are provided training in consumer engagement so that, over time, they can assist other staff to perform engagement activities.
 - b. Basic training for all staff to raise awareness of consumer engagement, its benefits and the process for incorporating engagement activities within programs, projects and services.
2. Extend Consumer Engagement Lead role to lead the implementation of the Consumer Engagement Plan, monitor engagement activities and apply process improvement activities.

Monitor engagement and evaluate impact

Evaluating the impact of consumer engagement and what the experience was like for all (consumers and NPS MedicineWise staff) is essential to assess how successful the process was and where improvements can be made. Evaluations should reflect on all stages of the project, as well as at the end of the project or activity.

There are three levels of evaluation that can be used to assess the impact of consumer engagement: Evaluation of the process, impact and outcomes.

- ▷ Process – Focus on the processes of partnering, and the immediate impacts. For example, how was the experience for consumers and staff, who else was involved, and their relevance to the process and levels of satisfaction.
- ▷ Impact and influence – Focus on the short-term impact of partnering, measuring against the aims and objectives of your project. Also, consider any unanticipated effects and how you navigated these.
- ▷ Outcomes – Focus on the long-term outcomes, and the overall goals with a broader outlook. Did the partnering fulfil its purpose? Did you achieve what you set out to do?

An evaluation plan will be collaboratively developed once this document has been approved.